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Experiences of Transgender Adults Navigating Healthcare Access in Massachusetts

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Submitted in Partial Completion of the
Requirements for Departmental Honors in Social Work

Bridgewater State University

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Abstract

Recent research studies regarding Transgender individuals' experiences of discrimination in health care settings strongly recommend the value of qualitative data, and the need for research into how transgender patients find, obtain, and access medical care, preventatively and as needed. However, despite calls for qualitative data, limited qualitative studies have focused on medical access and experiences of transgender patients as of 2019. This exploratory qualitative study utilized semi-structured qualitative interviews conducted between May 27th, 2019 through August 10th, 2019 to ask about the experiences of transgender individuals as it pertains to accessing health care services in Massachusetts. Participants ($n=8$) were recruited through convenience and snowball sampling methods, and the resulting narrative data was analyzed using Grounded Theory. Presented information will include the research process/methodology, literature review including the history of the evolution of trans-healthcare and will review the consistent themes and access model discovered. Theory created from this data, and the coded data itself, can be utilized to better inform healthcare access including materials, policy, and quality of care for transgender adults accessing healthcare in Massachusetts.

Keywords: Transgender, Healthcare, Access, Discrimination, Massachusetts, Primary Care Provider, Trans-knowledgeable, Medical

Experiences of Transgender Adults Navigating Healthcare Access in Massachusetts

Introduction

For many individuals, the life event or circumstance which warrants a need for accessing healthcare is inherently stressful. The process of seeking or receiving medical treatment is not always simple or intuitive. For transgender (trans) and gender-non-conforming (GNC) individuals, there is an added layer of fear for their comfort, dignity, and safety. Historically, approximately 30% of trans-identified adults report incidents of discrimination, up-to and including assault, while accessing healthcare services (Lambda Legal, 2010; Grant, et al., 2011; James, et al., 2016). Despite this prevalence of negative experiences, as of August 2019 there are few qualitative studies available to give depth and humanity to these statistics.

Identifying the population

Over the last decade, quantitative studies have been conducted to determine the scope of discrimination experienced by transgender individuals, however few studies exist outside of this focus. From these projects, for the first time in history, data is available regarding the intersectionality of transgender identities and the rates of varying discriminatory life experiences had by transgender people in certain environments and circumstances.

Overwhelmingly, studies show that trans individuals delay necessary medical care due to risk factors and fears related to their gender identity, and over half of all trans individuals report needing to educate their medical provider/team on the realities of their health care needs (Lambda Legal, 2010; Grant, et al., 2011; James, et al. 2016). About 30% of respondents in multiple surveys report having experienced some form of discrimination from a medical provider due to their gender identity, including reports of physical and sexual assault occurring in medical settings (Lambda Legal, 2010; Grant, et al., 2011; James, et al., 2016). Based on a National

Center for Transgender Equality survey (2015), 8,400 respondents experienced some form of discrimination, with approximately 280 individuals likely experiencing some form of physical or sexual assault based on survey data (James, et al., 2016).

Picture of healthcare access in Massachusetts/USA

According to a study published in 2017 by the Center for Disease Control and Prevention, across the nation approximately 82.7% of adults age 18-64 have access to ongoing medical care outside of emergency medical providers or establishments (Centers for Disease Control and Prevention, 2018). As of the 2019 census, Massachusetts was home to just under 6.9 million residents (United States Census Bureau, 2019). There are no existing standardized methods of data collection for identifying the transgender population in Massachusetts, or at the Federal level, leaving too many unanswered questions regarding the health and safety of trans individuals in Massachusetts.

The 2016 Williams Institute study on Transgender Population in the United States asked if participants self-identified as transgender, and to further break down their binary gender identity, which resulted in an estimate that approximately 0.6% of individuals in the United States over 18 identify as transgender (Flores, Herman, Gates, & Brown, 2016). The 0.6% population estimate has been the approximate standard used for policy and advocacy measures nation-wide and would indicate a population of approximately 41,000 trans individuals in Massachusetts.

A 2017 Accelerating Acceptance survey published by GLAAD (2017) found a much higher self-identified rate of trans identity, at about 3.5% for those between the ages of 18-71. This study obtained participants through online polling, and offered a variety of gender identity labels for participants to select from, including cisgender, agender, transgender, gender fluid,

bigender, genderqueer, and unsure/questioning, with the population modeling done solely for individuals who self-identified as transgender (GLAAD, 2017). The inclusion of both studies creates a wide population estimate range for trans adults in Massachusetts, between 41-238,000 individuals. Both surveys utilized an online survey method, however GLAAD is an active and well-established LGBTQ+ advocacy organization, and their role as a public advocate may have led to a higher saturation of trans-identified survey participants than typical similar surveys.

In the Boston area, where the largest provider of Transgender Health Services has become established through a partnership with Beth Israel Deaconness Medical Center, the Boston Public Health Commission (BPHC) found that between 2010-2017 approximately 0.7% of the Boston adult population self-identified as transgender, roughly 5,000 individuals (Mather, Mehta, Wada, Ayanian, Manukyan, & Dooley, 2019). Looking more closely at the intersectional identities of trans individuals in Massachusetts, the BPHC reported that “40.0% were White non-Latinx, 28.1% were Latinx, and 31.9% were another race/ethnicity (Mather, et al., 2019).”

In Massachusetts, the average number of licensed active primary care physicians per 100,000 residents is 247.4, significantly higher than the national average of 159.6 PCPs per 100k residents (United Health Foundation, 2019).

Legal Landscape for transgender health care

Currently in the United States, there are few states with anti-discrimination legislation written intentionally to protect trans and GNC people from experiencing discrimination while receiving or seeking medical care (Movement Advancement Project, n.d.). Additionally, there are few, if any, legal or criminal repercussions in any U.S. state for discrimination against trans individuals in medical settings. The rights of trans individuals in the United States appear to be in flux with current legislative efforts and existing policies and legislation redefined frequently.

As of this project, the following federal legislative protections exist regarding discrimination of trans individuals seeking healthcare:

Table 1

Federal Legislative Policies in place for Trans Individuals in Healthcare Settings

<i>Name</i>	<i>Action taken in</i>	<i>Overseen by</i>	<i>Content</i>
Legislation: “Affordable Care Act”	2010	<i>Federal Government (Enacted)</i>	<i>“It is illegal for medical providers to discriminate against individuals solely based on their transgender identity.”</i>
Federal Rule: “Nondiscrimination in Health and Health Education Programs or Activities”	2019	<i>Federal Government (Enacted)</i>	<i>This rule removes language and policy within the Centers for Medicare & Medicaid Services which previously protected LGBTQ+ patients from discrimination while accessing healthcare.</i>
HR 5 “The Equality Act”	2019	<i>Approved by the House of Representatives and awaiting Senate review</i>	<i>A package of civil-rights policies regarding equal access and opportunity for LGBTQ+ individuals, as well as anti-discrimination policies which would outline consequences for discriminatory behavior.</i>

Note. The above legislative policies reviewed represent a snapshot of the existing enacted federal legislation as of the completion of the research study. State and local policies may differ, and there are many forms of legislation at the State and Federal level which are not yet enacted.

Federal and state laws also exist to prevent medical insurance providers from denying access to medically necessary transition related services, however there are some exceptions, and these laws may not apply to all public and private insurers equally (National Center for Transgender Equality, n.d.). In June 2019, the Centers for Medicare & Medicaid Services

published a federal rule which would effectively overturn federal anti-discrimination policies intended to protect LGBTQ+ individuals accessing healthcare (Patient Protection and Affordable Care Act, 2019). This action is one of several pending or recently implemented rules and policies which remove language regarding discrimination of LGBTQ+ persons in healthcare, housing, and other federally supported or funded services (GLAAD, 2019; National Center for Transgender Equality, 2018; HHS Office of the Secretary, Office for Civil Rights, 2018).

As of the time of this study, a new piece of legislation, HR 5, commonly referred to as the Equality Act, is pending approval by the U.S. Senate as of May 27, 2019 (HR5, 116th Congress) and has been referred to the Committee on the Judiciary, with no further scheduled actions pending (House HR 5, 116th congress, 2019). In the meantime, by removing references to LGBTQ+ policies and protections on public facing websites and content controlled by the United States Government, an already vulnerable population becomes even less able to self-advocate and stay up to date on legal protections and restrictions.

In 2018, Massachusetts voters were asked to determine the outcome of a rare referendum, by voting to uphold existing anti-discrimination legislation that had already been successfully signed into law two years prior (Galvin, 2018). The measure passed with only 67.8% of the votes (Galvin, 2018), a sobering message to the Massachusetts trans communities which was only partially remedied by the Conversion Therapy Ban HR140 Law being signed by Governor Baker in April 2019 just as this study was being developed (HR 140, 2019).

History of Trans Healthcare Access and Rights

Historically, trans medical access rights and advancements have been furthered by single individuals with power and influence, and not by government entities. This dates to the creation of the Erickson Educational Foundation (EEF) in 1964, funded by millionaire philanthropist

Reed Erickson, who also happened to be transgender (Devor, & Matte, 2007). The EEF had three primary foci, one of which being the pursuit of medical advancement and research of topics deemed to be too controversial for the medical community at large, such as topics related to transsexualism (Devor, & Matte, 2007). Erickson received his own transition-related medical care from renowned trans-knowledgeable medical specialist Harry Benjamin. Dr. Benjamin had come to international attention following his work in support of the first documented vaginoplasty, performed on World War II veteran-turned celebrity, Christine Jorgensen, in 1952 (Rosario, & Meyerowitz, 2004). With this notoriety and the resulting publications and research, the term “Transsexual” was first used in a medical capacity to refer to an individual born and assigned one gender, but who suffered from dysphoria resulting from an internal identification of the opposite sex that they were assigned at birth (Benjamin, 1954).

The EEF went on to create the Harry Benjamin Foundation, with Benjamin crediting Jorgensen’s public transition as key to his work and further research (Devor, & Matte, 2007). Benjamin, along with noted sexologist Alfred Kinsey created the first gender clinics in the United States and supported the creation of the Harry Benjamin International Gender Dysphoria Association (HBIGDA) in 1979 (Denny, 2002). The HBIGDA established itself throughout the eighties as the first of its kind in research, policy advocacy, and provision of medical care to trans individuals (Denny, 2002) by publishing the Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming people for the first time in 1979 (Carroll, 1999; Denny, 2002).

The Harry Benjamin International Gender Dysphoria Association is now known as the World Professional Association for Transgender Health (WPATH) (Denny, 2002), and published the most recent Standards of Care in 2012 (Coleman, et al., 2012). These standards of care are

used internationally today to support the ethical and appropriate medical care of trans individuals (Denny, 2002). The Standards of Care, and Benjamin's work, is arguable the largest first positive step in trans healthcare access in United States history and remains relevant and a best practice in multidisciplinary care and treatment of trans patients (Denny, 2002). The field of trans-knowledgeable healthcare has evolved rapidly since the first publication of the Standards of Care in 1979, however policy and legislation remain largely unchanged from that time according to the Movement Advancement Project. In fact, in the 1980 edition of the Diagnostic and Statistics Manual, edition three, a new psychiatric diagnosis for those experiencing cross-gender behaviors, urges and tendencies was published, creating a pathology of "gender identity disorder" (Drescher, 2010).

Since the initial publication of the DSM-III with the inclusion of gender identity disorder, the newer DSM-IV has also been released as of 1994 (Drescher, 2010). Critics of the medicalization and pathologizing of trans identity claim that the DSM classification enabled continued stigmatization and created barriers to life-saving transition care (Drescher, 2010). As of 2013, the DSM-V has re-classified gender identity disorder as the newly classified "gender dysphoria," following recommendations from the Standards of Care from the World Professional Association for Transgender Health (Fraser, et al., 2010; Drescher, 2010). Despite this change, the International Classification of Diseases (ICD-10) still includes several pathologies related to trans identity and will continue to do so until the publication of the ICD-11 in 2022, despite recommendations against this practice. (World Health Organization, 2019; Drescher, 2010)

Defining the research question

Massachusetts has been on the forefront of mainstream medical and legislative advocacy throughout history. Given that Massachusetts is home to a population of trans adults with

estimates between 41,000-238,000 (depending on population modeling), there has been a lack of legislative evolution around anti-discrimination policies.

While there is some quantitative data to show the clear ongoing quality and access challenges faced by trans patients, there is little qualitative data of trans patients' experience. There was an apparent lack of research around the intersectional identity of trans individuals, combined with direct calls for new qualitative/narrative study materials to better understand the lived experience of trans individuals as they access healthcare (Lambda Legal, 2010; Grant, et al., 2011; James, et al., 2016). The resulting research question formulated for this study was: How are adult transgender patients navigating the existing healthcare system to access medical care in Massachusetts?

Literature Review

Defining "Transgender." the Lambda Legal team within their 2009 study broadly defines Transgender individuals as being: a person who transitions "from one gender to another, and those who may not, including genderqueer people, cross-dressers, androgynous, and those whose gender non-conformity is a part of their identity" (Lambda Legal, 2010). As of 2013, the DSM-V utilizes a diagnosis of gender dysphoria to support transition related medical care, and the American Psychiatric Association defines this as: "a conflict between a person's physical or assigned gender and the gender with which he/she/they identify" (American Psychiatric Association, 2016). People with gender dysphoria may be extremely uncomfortable with the gender they were assigned, sometimes described as being uncomfortable with their body (particularly developments during puberty) or being uncomfortable with the expected roles of their assigned gender (American Psychiatric Association, 2016)."

Trans individuals begin to self-identify as such at a variety of ages and life-stages, often not having a true name for their experience, but still recognizing an internal disconnect from expectations associated with their assigned sex and gender (Steensma, et al., 2013; James, et al., 2016). A 2015 study conducted by the National Center for Transgender Equality found that 60% of the almost 28,000 individuals surveyed experienced some form of disconnection to their assigned gender at birth, as early as age 10 or younger (James, et al., 2016). Further studies have found a correlation with the intensity of gender dysphoria in childhood and persistence of gender dysphoria and gender nonconformity in later adulthood (Steensma, et al., 2013). When it comes to acting on those feelings associated with their gender identity, 43% indicated taking or intending to take actions to medically and/or socially present in the gender they most identified with also known colloquially as transitioning, between age 18-24, and 24% between age 25-34 (James, et al., 2016).

The American Psychiatric Association refers to the use of medical interventions to support biological gender-affirming changes as a form of treatment for gender dysphoria, primarily using hormone replacement therapy and surgery (American Psychiatric Association, 2016). This medical transition strategy is often supplemented by social and legal transitions (American Psychiatric Association, 2016), often with overlapping requirements of medical treatments, such as gender affirming surgeries, as a requirement to obtain changed gender markers on a birth certificate (Movement Advancement Project, 2019). Some advocates for trans reproductive rights claim that this overlap of government regulation of trans bodies is a form of modern coerced sterilization (Nixon, 2013). For the purposes of this study, questions asked of participants were focused not specifically on transition related medical care, but on the experiences of accessing healthcare of any kind through the lens of being a trans-identified

person. To develop an effective interview tool, the largest existing data sets on trans discrimination were reviewed:

The 2011 National Center for Transgender Equality study was the first large scale qualitative study focused entirely on identifying the scope, frequency, types, and severity of discrimination faced by trans and GNC individuals across all areas of daily life, including school, work, and family (Grant, et al., 2011). Data shows that the majority of the 6,400 transgender people surveyed felt that most of the time, if ever, people could not “tell” or identify them as transgender without being explicitly told, which was a significant protective factor correlated with lower rates of discrimination (Grant, et al., 2011). Further, 41% of the 2011 respondents indicated that they are not “out” as being a transgender person to anyone on their medical team (Grant, et al., 2011). Often this is due to fear of lost relationships and discriminatory or negative reactions, including concerns over the quality and type of care that would be offered to the patient after disclosing their identity (Grant, et al., 2011).

Of note, an individual’s status as not being out as a transgender person may also indicate that they have either chosen not to or are unable to medically and/or socially transition. Alternately it could also mean that they have pursued a medical and/or social transition and live at least part of the time as the gender they identify as, without publicly declaring that they are doing so (Lambda Legal, 2010; Grant, et al., 2011). The ability to hide one’s transgender status can only go so far when seeking medical treatment however and can become a complicating factor of seeking medical care.

Among transgender people, studies show that approximately half of transgender individuals were assigned female at birth (AFAB), and half assigned male at birth (AMAB) on their birth certificate (Grant, et al., 2011; James, et al., 2016). As represented by the most recent

data from the 2015 National Center for Transgender Equality study of approximately 28,000 individuals, the transgender population is predominantly White, with 12.6% identifying as Black, 16.6% identifying as Latino/a, 5.1% Asian, 2.5% Multiracial, and 0.7% American Indian and 0.4% Middle Eastern (James, et al., 2016).

When compared against the United States census general population of 2015, geographic distributions of trans individuals are proportionate to population density throughout the United States, with exception of the Southern regions of the US, which have fewer concentrations of trans individuals comparatively (James, et al., 2016).

English as the only language spoken in the home was indicated by 84% of trans households in the American Community Survey of 2015 within the U.S. Census, however in households that spoke a language other than English (either as a secondary or primary language) Spanish was the predominant common language.

Looking at education and professional experiences, according to these data sets, trans adults are likely to be educated beyond high school, with only 2% not completing high school (James, et al., 2016), down from same cohort measured at 4% in 2011 (Grant, et al., 2011). Despite the 47% majority of secondary degree-holders (James, et al., 2016), individual income among transgender survey respondents is significantly lower than the national average, with 55% earning less than a \$25k annual income, compared to only 49% of the US adult population (James, et al. 2016). For those individuals who can secure stable employment, and completion of a secondary education, 9% of trans individuals reported annual incomes of \$100K or more (James, et al., 2016).

When considering access to healthcare overall, 86% of trans individuals reported being covered by health insurance, however this was slightly less than the average general population

of Americans, with trans people of color (POC) reporting much higher rates of being uninsured (James, et al., 2016). Despite having similar access to insurance as the general population, 24% of trans individuals indicated barriers to appropriate care based on their gender identity or status as a trans individual (James, et al., 2016), these services were most often related to name and identification related changes, transition related health care, and reproductive and/or preventative health screenings (James, et al., 2016). When specifically asked about barriers to healthcare, 33% cited cost of receiving care, with significantly higher numbers among trans POC (James, et al., 2016). The second most significant barrier to healthcare access was perceived risk of being disrespected or mistreated as a trans person, which was reported by 23% of study participants in 2015, or 6,440 individuals (James, et al., 2016). Another significant barrier to healthcare access was the availability of trans inclusive providers in a geographic area, with trans individuals more than three times as likely to travel in excess of 50 miles for transition-related care (James, et al., 2016). This information was especially notable when considering the geographic layout of Massachusetts, and the scarcity of high-quality medical care outside of the Boston area, when compared with the availability of accessible public transit.

Methodology

Development of study materials

This research is an exploratory qualitative study, consisting of semi-structured interviews and utilizing grounded theory to analyze the results and answer to the research question. The researcher developed a seven-question interview survey, using open ended explorative questions. Semi-structured questions involved a primary question, with pre-approved sub-prompts to explore the content of the answer within an open-ended format, while still maintaining similar core areas of discussion (see Appendix (A)).

A demographic screening survey was developed utilizing the National Center for Transgender Equality's 2010 and 2015 surveys as a guide. The demographic questionnaire focused on identifying the participant's age, sex assigned at birth, current gender identity, level of education, level of medical insurance coverage, identity as a transgender person, preferred pronouns, and status of any legal transition processes related to documentation and social changes such as driver's license and birth certificate name and gender marker changes. The demographic questionnaire also asked a question about chronic or ongoing healthcare needs; however, this was the only question asked about healthcare access or needs in this portion of the interview (see Appendix (B)).

Recruitment

Following approval by the Bridgewater State University (BSU) Internal Review Board (IRB), recruitment was done using convenience and snowball samples, with a goal of interviewing a minimum of ten individuals from Massachusetts. A recruiting letter was created detailing the voluntary nature of the study, risks, and benefits of participation, and outlining the purpose and intended usage of the data, and the data collection and analysis process (see Appendix (E)). Due to the student researcher's identity as a member of the lesbian, gay, bisexual, transgender, queer and adjacent/aligning/allied (LGBTQ+) community, as well as a gender non-conforming and transgender identified person, some exiting connections to the community were logical avenues for recruiting and interviewing.

Recruitment occurred between May 27, 2019 and August 1, 2019, with a resulting sample of 8 eligible transgender adults. Criteria for inclusion in the study included: self-identifying as transgender, accessing, and receiving healthcare in Massachusetts, and being age 18 or over. All participants were provided with a written informed consent document approved

by the BSU IRB, which was also reviewed verbally (See Appendix (C)). The student researcher obtained both written and verbal informed consent to participate.

Recruiting involved direct contact, both through face to face discussion, and electronic communication, with transgender individuals from within the student researcher's geographic and community connections across southeastern Massachusetts. As a member of the community, the researcher also utilized attendance at events focused on the LGBTQ+ community (also referred to as the Queer community) to recruit potential participants. This included engaging with transgender-owned and operated businesses and organizations focused on the support and advocacy of transgender communities and individuals.

The research created a digital recruiting flyer utilizing information and language from the IRB approved recruitment letter, which was shared directly within online communities that the student researcher is active within, with the permission of group leaders and participants (See Appendix (E)).

Data Collection

Once consent was obtained, participants were provided the IRB approved demographic questionnaire, and engaged in a seven-question interview, which was conducted in a semi-structured qualitative format. The interviews were audio-recorded using a hand-held audio recorder, the audio content of which was immediately uploaded to the researcher's secure online cloud storage account.

Following the interview, which took approximately 45 minutes, participants were then provided with IRB approved debriefing materials regarding the rights of transgender patients in Massachusetts and the United States. Additionally, contact information and resources for transgender informed mental health supports were provided in the event of any adverse

emotional outcomes following the interview, due to the sensitive and traumatic nature of potentially reliving experiences of discrimination (See Appendix (D)). In appreciation for their involvement in the study, participants were offered a gift of \$10 value, which was funded through the Adrian Tinsley Grant for Undergraduate Research through Bridgewater State University.

Data Analysis

The researcher transcribed a total of 247 minutes of audio interviews. As they were completed, interview transcripts were then reviewed and coded utilizing grounded theory and constant comparisons, with line-by-line review of interview content which was labeled based on the emotions, actions, and general information occurring in each line of the interview (Charmaz, 2014). These initial codes were then compiled and pooled into more generalized axial/secondary codes which were found to be applicable across multiple interviews, constituting themes and concepts to be further investigated by the research team (Charmaz, 2014). Data analysis of demographic questionnaire responses was performed also, and trends between the interview data were quantified and analyzed using descriptive analysis and grounded theory, respectively.

Developing theory. With all eight interviews transcribed and coded, the researcher identified emerging themes and patterns of experience, which were then analyzed and explored further within the data comparatively and was also checked against existing study and literature materials relevant to the scope of the study, to determine if the data was sound and reflected existing identified trends of transgender experience.

Demographics

Gender Identity. A total of eight individuals participated in the study, all of whom self-identify as Transgender. Of these, seven were assigned female at birth (AFAB) and further self-

identify as Transgender Male/Masculine (Trans-Masculine) (6 out of 7 AFAB participants) and Genderqueer/Gender Non-Conforming (GNC) (1 out of 7 AFAB participants). There was one participant assigned male at birth (AMAB) who self identifies as Transgender Female/Feminine (Trans-Feminine). (See Table (2))

Age, Education & Employment. Study participants ranged in age from 20 to 48, with a mean age of 29.38. All the study participants self-identified as White/Caucasian. When looking at academic achievement, 5 of 8 indicated having completed “Some College” and 2 of 8 indicated completion of a bachelor’s degree. For employment, 5 of 8 participants reported current full-time employment, and 2 of 8 as being employed part-time. Only one participant indicated they were Seeking Employment. Half of the study participants also reported a current student status, separately measured from employment status. (See Table (2))

Healthcare needs. Regarding health care needs, participants were asked “Do you have any medical conditions or concerns which warrant ongoing or regular medical care with a medical provider?” Of note, during interviews it became apparent that due to status as a transgender person, undergoing transition of any kind (biomedical, social, legal) would warrant some degree of ongoing medical care as a requirement; this could include ongoing care to receive letters of medical certification for legal and social transition, or to receive biomedical or social/emotional professional support for any form of transition. This in and of itself may be considered a form of complex care based on the wording of the initial question, however only half of the participants answered this question affirmatively (indicating that this was not a universal unanticipated finding). For the purposes of this study, the ongoing medical needs associated with transition were not considered as an affirmative answer to the question listed above, regarding the need for ongoing medical care for complex healthcare or medical needs.

Ultimately, 4 of 8 participants indicated ongoing medical care which was defined as “complex care.” (See Table (2))

Transition and documentation status. When it came to transition itself, all study participants indicated they have pursued a biomedical and/or surgical intervention as a means of easing dysphoria related to their gender identity. Most participants (7 of 8) indicated that they are currently or have at some time been living full-time as their identified gender, during the context of the interview session. Most study participants had completed very few legal or documentation-related transitions. Four out of eight participants indicated that they had completed a legal name change, and the same four indicated completion of a gender marker change on a driver’s license. These four individuals overlapped both categories, however none of the 8 participants had completed a gender marker change on their birth certificate.

All participants indicated that discrepancies between documentations and usages of preferred names, legal names, birth names, and gender markers all created challenges when it came to accessing healthcare, and five participants stated that this discrepancy actively creates dysphoria. In four cases, this inconsistency and the provider’s inability to correctly manage these changes, resulted in the effected individuals receiving inaccurate and/or inappropriate medical care based on their biological needs. A further three participants stated that they typically “pretend” to be a cis individual in order to avoid dysphoria associated with coming out to medical providers. Five participants felt forced to come out to medical providers or members of the medical team in order to address inaccurate documentation, request accurate medical care, or explain medications during encounters, putting them in a confusing and uncomfortable position as the patient and educator, as well as being self-advocate. As reported by Participant 5, *“It’s a lot of contradicting people in one appointment, and by the end of it they’re kind of sick of you.”*

Overall, study participants were primarily Trans-masculine, (assigned female at birth, transitioning to masculine presentation, and using He/Him pronouns socially when/wherever possible) and in their late twenties (7 of 8). Participants were all white, insured, and were mostly employed, educated and/or currently pursuing education. Half of our study participants indicated formal and legal changes made as a part of their transition, however all participants discussed biomedical and social transition steps taken currently or historically, with an intent to continue to do so indefinitely or at some time in the future when possible. (See Table (2))

Insurance coverage. All study participants reported currently having health insurance coverage, with some participants mentioning challenges with insurance coordination of benefits for transition related medical care. At least one participant did report challenges with insurance companies while attempting to access medical care which was medically indicated for their physical body, but which the insurance company attempted to deny due to a change in the legal gender marker on the participant's identification and insurance policy. (See Table (2))

Participant five discussed the challenges of having a right to biologically necessary medical care:

Like if you go for a pap smear but you're registered as male, your insurance bills get bounced back... So, I've gotten in multiple arguments with billing people about such things, it's like no I deserve testosterone and a pap smear, really. I have the right to both of those things, I know it's confusing, but I should get both. (Participant five)

Table 2

Demographic Results

<i>Preferred pronouns</i>	<i>Sex assigned at birth</i>	<i>Gender presentation</i>	<i>Age</i>	<i>Race</i>	<i>Highest level of education</i>	<i>Currently insured</i>	<i>Employment status</i>	<i>Transgender self-identified</i>	<i>Gender ID descriptors chosen</i>	<i>Document changes made</i>
He/Him	Female	Male	21	White/Caucasian	High School Diploma/GED	Yes	Student; Part Time Employed	Yes	Transgender Male/Masculine	None
He/Him	Female	Male	20	White/Caucasian	Some College	Yes	Unemployed-seeking	Yes	Transgender Male/Masculine	None
He/Him	Female	Male	28	White/Caucasian	Some College	Yes	Full Time Employed	Yes	Transgender Male/Masculine	Legal Name Change; Gender Marker Change (Driver's License)
She/her	Male	Female	48	White/Caucasian	Some College	Yes	Full Time Employed	Yes	Transgender Female/Feminine	Legal Name Change; Gender Marker Change (Driver's License)
He/Him	Female	Male	34	White/Caucasian	Bachelor's Degree	Yes	Full Time Employed	Yes	Transgender Male/Masculine, Transsexual; Genderqueer; Genderfluid; Gender Non-conforming	Legal Name Change; Gender Marker Change (Driver's License)
He/Him	Female	Female	21	White/Caucasian	Some College	Yes	Student; Part Time Employed	Yes	Transgender Male/Masculine	None
He/Him	Female	Male	26	White/Caucasian	Some College	Yes	Full Time Employed	Yes	Transgender Male/Masculine	Legal Name Change; Gender Marker Change (Driver's License)
He/Him	Female	Male	37	White/Caucasian	Bachelor's Degree	Yes	Student; Full Time Employed	Yes	Transgender Male/Masculine	None

Note. The complete results of the demographic survey completed by all participants, in no particular order relative to their order of participation or participant number.

Results

Over the course of the study, three central concepts emerged from the narrative data. The first resulted in a model of accessing and identifying trans-knowledgeable healthcare providers. The second identified aspects of experiencing safety and comfort while accessing health care, and the third indicated a general concept that participants experienced health care as a privilege rather than a right of all individuals.

Experiences Accessing Healthcare

Length of primary care relationship. Seven of eight participants reported having an existing relationship with a primary care provider (PCP). Of these, six had been established for

about a year or more. Five of seven participants connected to a PCP reported having accessed their PCP for services within the last three months. The participant without an established PCP did report a recent need for medical treatment which required the support of a PCP, during that same three-month timeframe. The participant was held up when they needed access to specialist referrals or other ongoing services typically provided by a PCP, but which they were unable to access as a result of not having a relationship with a PCP. Without this relationship, patients must then rely on Urgent Care centers or Emergency Rooms for care. When discussing the options for accessing medical care due to an unexpected or urgent medical need, individuals consistently stated that without a primary care provider, the emergency room or urgent care was the typical option and two participants made comments about delaying care altogether due to fear. However, among individuals with a PCP relationship of approximately six months or more, the main concern was whether an appointment would be available within the time of need, and could they tolerate the stress of an urgent care visit if necessary. Among all participants, half (4 of 8) self-reported directly experiencing a transphobic or negative interaction based on their identity as a transgender person in emergency room and walk-in/urgent care settings. Participant Three shared insight on weighing the choice to delay urgently needed medical care due to the potential negative experiences and dysphoria:

Usually the only times in the past that I've needed like, you know immediate care like that, have been something more serious or I'm genuinely concerned about something. And in that case, based on where I live, my only options are either an urgent care center or like literally a hospital, depending on how severe I deem whatever it is to be... instead, what ends up happening is usually the first reaction as a patient, as an individual, is if something goes wrong, the first thought that comes to mind is can this wait? Like, can I

live, can I stick it out and set up an appointment for somewhere in the future or is this like life or death? That shouldn't be the thought process, but that's sort of how it is.

(Participant Three)

Participant One on hoping they can build a relationship with a primary care provider:

I don't even really know how the transition process, works. Legally and all that stuff. Like of course I've watched people go through it, but I don't really understand it. And when it comes down to that for me, I know at the point in my life, my family's going to be gone. I'm not going to have a person like that. So, I want to create that relationship in the health setting so that I can ask those darn questions, because I've never had a chance to in my life. (Participant One)

Compromising Identity for Care. Some participants reported actively “pretending” to be cis-gender, in order to prevent discriminatory experiences while accessing healthcare.

Participants could choose to disclose their identity and transgender status and out themselves immediately, thereby increasing the likelihood that they would experience some form of intentional or unintentional inappropriate and disrespectful questioning and/or interaction from a member of the medical team, up to and including “firing” providers due these instances, and/or delaying care as a result of preventing further experiences of discrimination;

Alternately, participants could choose to hide their identity, thereby preventing medical providers from making educated evidence based assessments of needs and medical treatment plans based on the known vulnerabilities of transgender populations, also preventing transition, and experiencing significant ongoing dysphoria during medical interactions – up to and including

delay of care as a result of preventing this consequential dysphoria. Participant six spoke on choosing to let people believe they are not trans:

Most people think I'm a butch lesbian. Because that's generally how I passively sort of look, so when I go into an urgent care situation, I am using my given name, and pronouns, and all of that, and all the documentation that goes with it... I would say yeah, that is a choice I'm making. Particularly because part of it is I don't want if I'm going to the doctor, to a doctor, for a stomach issue, I don't want to go to the front desk, give them my name and things like that, and then hand them a driver's license that doesn't match and then have to deal with that. (Participant 6)

Primary Care Access Model

Internal and External Motivators

Participants were asked to explain how they came to be established with their primary care provider, which resulted in two specific motivations which were defined by the researcher as: internal drive and external drive to seek a primary care provider. Internal drive refers to the participants' own internal motivations for seeking medical care through a PCP (5 of 7 participants), while external drive refers to circumstances such as insurance requirement, or the need for a referral to a specialist (2 of 7 participants).

Participants who indicated an internal drive for seeking medical care of any kind all identified the driving force as a need for transition related care, specifically hormone replacement therapy (HRT) or a physician's certification letter to access surgical transition to ease experiences of daily dysphoria. This internal drive was referred to as being "urgent," and participants also described battles with dysphoria and discrimination as drains on their mental

health and overall wellbeing. Participant 3 on the implications of delaying transition related medical care:

I wanted to definitely get an appointment set up as soon as possible, purely because I knew if I did not that I would be – end up putting it off for much further in advance, and it was something that I really wanted to make happen in my life, in terms of beginning that aspect of my transition. It was mostly for myself, that I needed to self-motivate, you know, to do that. And if I put it off any longer it wasn't going to happen, because I struggle with a lot of mental illness and stuff, and it was the kind of thing that if I didn't go for it, you know – set up an appointment within the month or something for example, it was just never going to happen and that was going to be worse for me. (Participant Three)

Of note, in total, 7 of 8 participants indicated that access to HRT or other transition related medical care is an internal motivator for seeking healthcare, regardless of their current connection with a PCP.

A key external motivator was finding and accessing care after aging out of a parent's insurance, aging out of a pediatric practice, or not being able to receive trans-knowledgeable care from a pediatric practice. Participants described a gap in care coordination which resulted in a challenge for these participants in establishing care with a PCP as an adult, independently.

Participant six illustrates this experience:

I was still seeing my pediatrician, and she has always been very nice and helpful and just overall a very good physician, but I do recall that when I was trying to – first starting to explain to her you know what I was feeling transition-wise she didn't really understand it. It was a difficult experience, not negative per se, she wasn't not-accepting of it, or

didn't make me feel bad or unsafe or anything like that. But I do remember it being kind of frustrating, because I got the sense that for however long that she had worked as a pediatrician she didn't really come across this that much, and didn't know how to respond to what I was telling her. She was like not informed enough about trans experiences or identities or anything that that entailed, so it was difficult because as a patient you go to physicians to try to get their input and get help from them and have them sort of tell you what to do and almost go for guidance sort of thing. But then when it's flipped and then you have to explain something to them it becomes kind of tricky and frustrating because you're not quite sure how to approach the situation anymore.

(Participant six)

Method for identifying trans-knowledgeable medical providers. Among all participants, a unique process of identifying and vetting a new potential medical provider was reported following the participant's internal drive to seek transition related medical care. Participants initially started with searches online focused on geographic location and transgender knowledgeability, determined by depth and extent of external/public facing trans-inclusive content they reviewed. Secondly, participants checked in on social media and with peers for references from individuals with similar needs and life experience (transgender, seeking transition related medical care or other specialized care, geographic location). Of note, three participants reported having been actively refused transition-related medical care from their existing primary care providers, in two circumstances this directly caused the patient to need to find a new PCP. Participant eight details the struggle of attempting to seek hormone replacement therapy through their existing PCP:

I started at my primary care, and she wasn't, she shot me down and said that she had never heard me talk about it before, and she didn't feel comfortable treating me or sending me to an endocrinologist. So, I just stopped going, and then I called Fenway, and it took like four months out to get an appointment. So, then I got my first appointment, and then she had to see me three times before I could get a shot, so – and there, also it's hard to get an appointment unless you really really need it. It took about, it took a full year to get on hormones after I started vocalizing it. (Participant eight)

Participant two discussed how a friend's social media post lead them to establishing care with a new provider based on feedback from social media:

Before physically changing my name, transition, that was you know not fun that I would have to get mail in you know that said my old name and my gender and everything. This isn't about me, but I have a friend, that he just got his name changed, and he's already had all of his surgeries, he was looking into the final stages of phalloplasty, and the people the billing people sent them his name, his preferred name on the statement. He put it on Facebook, he was all excited about it, because they knew he was trans and they took that into consideration, and I thought that was a pretty cool thing. (Participant two)

Lastly, based on the availability of providers geographically, and/or the limited availability of identified transgender knowledgeable providers, 100% of survey participants ultimately became a patient of, or at one point intended to become a patient of, Fenway Health in Boston, Massachusetts, regardless of their home location within the state. For several participants, the geographic limitation and financial costs associated with the burden of traveling to the Boston area were the largest obstacles to receiving trans-knowledgeable medical care, as the perception and reality both are that there is no such care outside of the larger city areas.

Participant five outlined their challenges trying to find a trans-knowledgeable PCP outside of Boston:

I have bounced around from one primary care to another. Either they won't call me by my name and my correct pronouns, or they're willing to but they're all the way in Boston, and I cannot afford the gas, the high co-pay, and the time off work, and paying for parking. I have to choose between a healthcare professional that respects me but costs me well over \$100 for a visit, or one that doesn't respect me and makes me incredibly uncomfortable and calls me by my deadname. (Participant five)

Additional findings of import regarding identifying medical providers were focused around geographic location, with participants from Western and Southeast Massachusetts (including Cape Cod & the Islands) reporting more significant barriers to accessing trans knowledgeable healthcare overall, of the following types: transportation access, financial/economic hardship including insurance incompatibility, and a high demand for trans knowledgeable providers resulting in long wait times to initiate care with a small number of available providers. Outside of trans-knowledgeable primary care providers, participants referenced that they would otherwise rely on endocrinologists as a specialist for transition-related medical care, or from local Planned Parenthood sites. As gender affirming healthcare services are offered at all Planned Parenthood sites according to their website, this creates some additional options for individuals in the Greater Boston and MetroWest Areas. However, as participant 3 expresses below, wait times are often long, and the Cape & Islands area continues to be under-served with no Planned Parenthood within 50 miles of most parts of Cape Cod:

I was trying to go with Planned Parenthood initially because I had I have been a lifelong supporter of planned parenthood and I was trying to set up something with them, I think

they have a branch in Boston. They were, they were just packed full and I think I came across that with a couple other places as well, where just like, there's such high demand for it and so few places to go that the places I did find were absolutely booked through for months and months and months in advance. It was impossible to get an appointment with them. (Participant 3)

Establishing the relationship with primary care providers.

When asked “how comfortable did you feel initiating care with a new provider,” participants had a wide range of responses. Among participants who were referencing initiating care with a provider they knew to be trans knowledgeable (through internet searching or references from the trans inclusive community), 75% of participants used the word “easy” and half used the word “comfortable.” Even the one participant who stated they initially felt anxiety establishing care with a known trans knowledgeable provider stated that once they began the process, things became “easy and comfortable.” Participant two reported:

What's made it positive has been if they were educated on being transgender. Just in general. If they were- if they understood how to identify you, you know using your pronouns. If they understand physical transition at all because it's been very positive when I go to my pcp and I don't have to worry about anything. [They] know my gender and the surgeries I've had, and what that all means. (Participant two)

Conversely, among individuals who were establishing care with a new provider, of whom they did not know if the provider would be trans knowledgeable or friendly, responses included: “scary” and “hard.” Participant one reported:

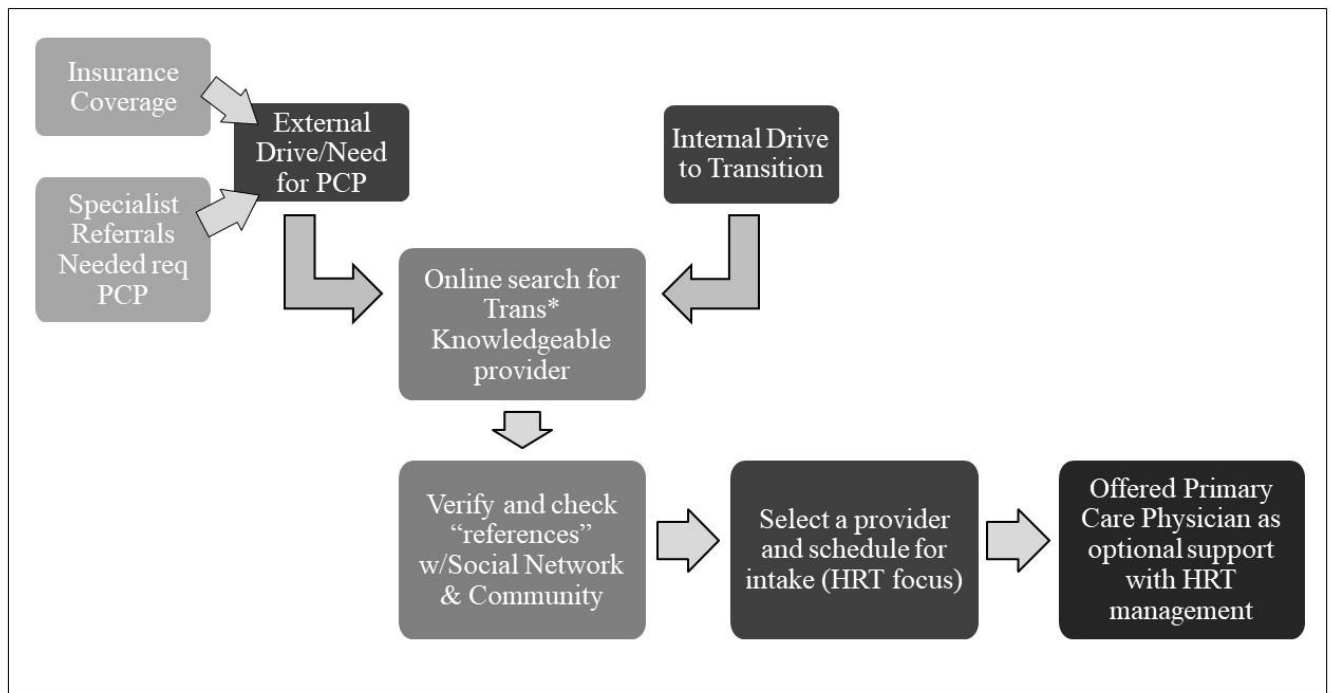
Doctors make me very uncomfortable as a trans person, because – I just know how unaccepting the health field can be. So I just stopped... it was pretty nervewracking. Cuz it was the first time I was seeing a physician in two years. (Participant one)

One participant described circumstances where they utilized an assertive tone or strategy to overcome the likelihood of negative experiences. This included intentionally coming out to the first contact during the first interaction (often while calling to inquire about availability) and informing the first contact of the expected terms of interaction, to prevent the opportunity for misgendering. Assertive strategies were also mentioned by participants as a method of trying to prevent members of the medical team from using incorrect/birth names, also known as “dead-naming.” Participant four describes the choice to use an assertive strategy with the first contact at a new provider:

I never changed my voice as part of the transition. So, I was running into a lot of issues on the phone with people calling me sir, and even if I told them what my name was, I would still get called Mr. LASTNAME. So I took a pre-emptive approach to dealing with people on the phone, where they would ask my name and I would tell them my last name is ____, my first name is ____, and I prefer to be called Ms. LASTNAME or Ma'am. So, I don't even give them the opportunity to make that mistake. (Participant four)

The following visual model was created which illustrates the process described above. Starting with both the internal and external motivators to seeking medical care of any kind and resulting in a relationship with a trans-knowledgeable primary care provider. (See figure (1))

Figure 1.

Primary Care Access Model

Note. The Primary Care Access Model depicts the flow of the process identified by survey participants. Due either to an external motivator such as specialist referral requirements or insurance coverage requirements, most participants sought care with a new medical provider in order to pursue medical and/or surgical transition related medical care. With the motivation generated from the external or internal drive, participants utilized online searches for transgender medical providers. Evaluation of public facing materials was key, but ultimately, obtaining “references” from others within the LGBTQ+ and Trans identified communities was a major determining factor in which provider was selected and contacted to initiate care. Primarily, study respondents were initiating care with a new provider specifically to pursue hormone replacement therapy (HRT) to ease dysphoria, typically provided through a specialist such as an endocrinologist. Once at the appointment and after reviewing the informed consent process, participants were offered the option of receiving routine healthcare and preventative

care with a primary care physician within the same practice, offering both transgender specific medical care as well as routine preventative care, through the same provider. This resulted in an ongoing relationship with a trans-knowledgeable provider.

Experiencing Safety and Comfort While Accessing Healthcare

The participants identified experiences of both safety and comfort while accessing medical care. Safety was identified as one's feelings and expectations of physical and emotional safety while accessing care. Comfort was identified as a more subjective perspective and experiential feelings of ease, confidence in the provider, and feelings of welcome and inclusion. These trends were most observable in the following aspects of the data, starting with self-reported incidences of transphobia as well as the types of observable signs of comfort and safety that participants reported. Participant six discusses how a positive and trans-knowledgeable first contact can positively impact patient access experience:

The scheduler at the gender clinic here in my college town, I love her, she's wonderful, every time I call she's very knowledgeable about her job and about how and specially because I was a new patient and it was a new avenue of healthcare for me, and I didn't know a lot of what I was doing, however she was very knowledgeable and very helpful. And she was very good at helping me get what I – about answering the question that I was trying to ask and not necessarily the one I was asking... she made sure to check in on things like name and pronouns, which I find especially important at a gender clinic.

(Participant six)

Defining Trans-knowledgeable prior to the appointment. For most participants, in the first interaction with the first contact, determinations needed to be made immediately regarding

the trans-knowledgeability of a new provider, the safety of the setting and interactions, and the comfort the individual could reasonably expect from interactions with the medical team. This was described as being a decision made even within the first phone call to the office, with the initial search results and public facing online presentation of trans-inclusive information, or lack thereof, sometimes also disqualifying providers prior to first contact. The need to make an immediate decision regarding the safety and comfort of seeking care with a new provider was reported to also carry beyond the initial visit. Participant one reported:

I'm an adult but going to the doctor's is scary, and I wish that more people would be aware of that and be more sensitive to that, especially for our community, the LGBT community. And be more reassuring and helpful with that. (Participant one)

Observable signs of trans-knowledgeability and inclusivity.

As reported previously, participants engaged in intentional searches for trans-knowledgeable medical providers, using online search engines as well as “crowdsourcing” recommendations from social media and peers/friends, when possible. Without the advance knowledge that a specific provider is trans-knowledgeable and inclusive, individuals looked for signs of intentional inclusion in waiting room materials, language use, and signage/forms with gendered and assumed information about the types of patients the office serves. Participants universally reported being positively impacted by visible signs of trans inclusion such as flags, stickers, or LGBTQIA+ inclusive signage and language, including marketing materials, research study advertisements and health-related pamphlets. Language used consistently to describe feelings in these kinds of intentionally inclusive environments was often “safe” and “comfortable.” Participant seven reported how knowing a provider is trans-knowledgeable and

inclusive through following the pre-appointment process helped them to feel comfortable accessing care:

I think I knew ahead of time that they were lgbtq friendly, so I automatically was just comfortable with them like right off the bat. I think having that established kind of, feel to them made me comfortable because I was like okay, all the other- or a lot of the other trans people are going here. This is where they're getting help, so I know for me that this is gonna be helpful for me, to further my transition. (Participant seven)

Participant three similarly observed:

The first things that sort of helped put me at ease were, for one thing it was a very professional smooth-running environment. Everyone there really knew what they were doing, it was, everyone was friendly and easy to talk to. All the steps involved of you know filling out paperwork and stuff were very easy and clearly explained, it felt comfortable, safe, that kind of thing. They asked for pronouns and things like that and preferred name which helped as well cuz that let me know that I was in a place where I was going to be respected. (Participant three)

Self-Perception of Transphobic Incidents

It was noted that during the course of the interview questions, 100% of the participants reported at least one instance of accessing medical care which was considered by the researcher to be uneducated at best and discriminatory at worst, with an overwhelming frequency of reported “inconveniences.” These inconveniences as described by participants included instances of pharmacy employees refusing to use or accept paperwork from a provider with a preferred name or refusing to use utilizing preferred pronouns. Additional examples included being a

witness to providers discussing the added stressors of coordinating care between providers and care systems when a patient has a preferred name or a legal name change.

Participant five discusses navigating systems of care after a legal name change resulted in inconsistent and invalid name and identification documents during an emergency room visit:

I was told that they had to go by their forms in their computers even though my insurance card, my ID, everything else says my correct name. So for the first 20 minutes I was having a panic attack, not about whether or not I could walk and go to work and all these things, but whether or not I was going to spend hours in the ER being dead-named because I couldn't emotionally take it. (Participant five)

When explaining the process of accessing healthcare, participants often referenced “having to come out” or correct members of the medical team who assumed or intentionally utilized incorrect or out-of-date names, gender designations and pronouns, and health information related to their transition or status as a transgender person. This process was described as causing significant anxiety (all participants), up to and including panic attacks for some. Participants reported instances of being forced to publicly correct medical providers or team members, such as the following example of participant two discussing experiences with visiting nurses following genital surgery:

A nurse came into my house and she didn't know anything about the surgery, didn't even really know what to be looking for. She just said 'well I know what infection looks like' – and she said a couple things that made me cringe and one thing that I really remember is that, she asked me, she was like 'so, I have a question. Why do some people...' and she

didn't know the word, and I filled it and was like 'transition' and she's like 'yeah. just to date the same sex.' (Participant two)

Participant one on how dysphoria being triggered creates discomfort:

It would make a difficult experience if they had to use my legal name and things like that and, just uncomfortable questions about my reproductive health. For sure, asking about my period and things like that and, sex life, even which they don't really but. Anything that would give me dysphoria. (Participant one)

It is interesting to note, despite 38% of participants directly stating that they had no perceived negative experiences accessing healthcare when asked, 100% of participants ultimately reported at least one incident of disrespect, harassment, and transphobia, up to and including being kept from appropriate medical care, being refused care due to status as a transgender person, being asked inappropriate and unnecessary medical questions regarding the individual's genitalia or sexual preference, etc.

Experiencing Healthcare as a Privilege and not a Right.

While analyzing the narrative data around the negative and positive experiences had while accessing healthcare, it was found that 63% of participants actively indicated some form of gratitude, or feeling lucky that they had not experienced significant negative experiences, despite 100% having indicated in some part of the interview an interaction or experience that was negative or transphobic as described. This internal perception that they are not only lucky to have not experienced any more significant issues, combined with the realities described by these participants, warrants further study around trauma, mental health, and resilience in transgender

adults seeking medical care despite discrimination, micro-aggressions, and occasional outright refusal of care.

Participant Two on being hopeful that the next medical visit won't be terrifying:

Just because I don't know what I'm going to run into, I have had mostly positive experiences, but I've also had those negative experiences where it's terrifying. So, no matter what, I get scared for any kind of medical visit. (Participant two)

Participant two later in the interview also directly expressed being grateful for the medical care they receive in Massachusetts: *"I think Massachusetts is doing a really good job with you know, providing medical care for trans patients, and yeah. I am glad to live where I live."*

Participant three on their experience from a perspective of privilege and appreciation:

I don't think my experiences are anywhere near universal because I feel that I've been overall very very fortunate and have had generally positive experiences apart from the things that I mentioned. And I've heard just talking to friends and loved ones about their experiences and hearing what other people within the trans community go through. I definitely get the sense that positive experiences are much less common than would be preferred. You know it's usually a lot more difficult for people to receive healthcare in a quick and safe manner, and – oh and also the fact that I also feel it's important to mention that I think that a lot of that has to do with the fact that I am in a more privileged position given that I am not disabled, I am not a person of color, I am relatively middle class, all of that I think has generally aided me and allowed me to have an overall

pleasant experience with healthcare, compared to the people who would not be in these positions. (Participant three)

Discussion

The purpose of this study was to identify how transgender adults in Massachusetts are navigating the existing healthcare system to access medical care. Through the process of interviewing the study participants and analyzing the resulting data, several answers have been generated which answer this question. Namely, an access model was created which outlines the method of identifying a new primary care provider (see Figure (1)).

Primary care access model

Internal and External Motivators

When considering the many reasons for connecting with a PCP, the majority of participants ultimately connected with a PCP in order to pursue transition-related medical care, driven by their internal motivation to transition. Our study confirmed that a primary internal motivator for seeking medical care is to ease dysphoria through medical and/or surgical transition. With an understanding from the literature that for many trans individuals, taking steps towards transition-related medical care, barriers of “financial constraints, safety concerns, fear of discrimination and rejection” (Grant, et al, 2011) are often insurmountable, especially among people of color (Grant, et al., 2011; James, et al., 2016). The external motivators for seeking primary care relationships were not the focus of the literature reviewed.

PCP relationships.

The results reviewed the relationship between long term relationships with a PCP and the likelihood of having a negative experience related to trans identity while accessing healthcare. Individuals with an established primary care provider offered fewer unique examples of negative experiences accessing healthcare, and those that were discussed were often self-described more as inconveniences than as traumatic experiences. It was further observed that individuals with an established PCP stated that they would seek treatment for unexpected illnesses or injuries by contacting their PCP first, and being seen in that office as opposed to going in to an urgent care/walk-in center or emergency room. Over time, However, individuals with no established or current PCP, as well as those who reported inconsistent PCP relationships, were obligated to rely on urgent care/walk-in centers and emergency rooms or simply delay care indefinitely. Both the 2011 and 2016 Transgender Survey data sets found that for both experiences of discrimination and also refusal of care related to transgender identity, hospitals and emergency rooms were consistently found to be the environments with the highest rates of these incidents (Grant, et al., 2011, James, et al., 2016)

The literature reviewed for the research study found that in 2011, 41% of individuals surveyed were not out to anyone on their medical team as being a transgender individual (Grant, et al., 2011) down to 31% in 2016 (James, et al., 2016). This does reflect an overall positive trend towards more intentionally inclusive and welcoming policies and practices regarding trans-knowledgeable care among medical providers. However, approximately 23% of the 2016 survey participants reported delaying care due to fear of treatment (James, et al., 2016), a phenomenon which was better understood through the narrative data collected.

Developing the care access model. The common methods of identifying and establishing care with a new trans-knowledgeable provider was one of the earliest themes

identified. Awareness of how trans patients are ultimately connecting with PCP's is a key to delivering life-saving preventative care to a marginalized and underserved population. As noted above, longer relationships with a PCP reduce the reliance on methods of care access which are more likely to result in a negative experience such as emergency rooms and urgent care centers (Grant, et al., 2011; James, et al., 2016). Medical providers who are seeking to increase patient census of trans individuals have the opportunity to make changes to public facing policies, marketing materials and strategies, signage, and make improvements to the training and trans-knowledgeability of first line points of contact such as receptionists, billers, schedulers, and security personnel.

As of 2016, approximately 33% of trans patients receiving transition-related medical care did so through the use of a specialist outside of their routine healthcare provider, typically a PCP (James, et al., 2016). However, also in 2016, 51% of trans patients received both their transition-related medical care as well as their routine healthcare from their routine healthcare provider or PCP (James, et al., 2016). With the qualitative data reviewed along with the literature, there seems to be significant opportunity to streamline healthcare opportunities and protocols by combining the offering of transition related medical care within the offices and services provided by primary care physicians.

Experiencing Safety and Comfort Accessing Healthcare and Healthcare as a Privilege

The researcher asked participants to discuss their most challenging experience accessing medical care, which resulted in themes which illuminated the interlinking nature of experiencing safety and comfort for trans individuals accessing healthcare. Participants reported feeling grateful for the minimally negative experiences that they had endured compared to their awareness of both observed and stereotypically expected negative experiences of trans-identified

individuals accessing healthcare. The fears disclosed by participants are not unfounded, as the NCTE studies from 2011 and 2016 consistently show high rates of discrimination and refusal of care across multiple healthcare environments (Grant, et al., 2011; James, et al., 2016) The 2016 study by the National Center for Transgender Equality found that of the participants who had been seen by a medical provider within the last year, 33% reported “at least one negative experience with a doctor or other health care provider related to being transgender (James, et al. 2016).” Among other experiences reported by participants, the 2016 NCTE study found that 24% of respondents were obligated to teach or educate their medical provider in order to receive appropriate care, with 15% reporting invasive or unnecessary questions about their identity unrelated to the medical visit , and a further 8% indicating care or treatment refusal related to their identity or gender presentation (James, et al., 2016)

Given the fact that trans individuals who are medically transitioning through the use of hormone therapy are obligated to remain in ongoing contact with a medical provider in order to safely and legally transition, this is a concerning status quo and subconscious power dynamic with wide ranging possible consequences. The results generated from this study affirmed that trans patients experience safety and comfort as being intertwined. The fears discussed by participants were not related or limited to being assaulted per se but were focused on the internal emotional and physiological experiences of suffering through dysphoria as a result of accessing medical care. For many participants, the suffering of dysphoria is judged to be more impactful than delaying routine or even urgent medical care, unless it absolutely cannot be avoided. In 2016, the NCTE reported that 23% of its respondents had elected not to seek necessary medical treatment due to the fear of mistreatment related to their gender identity or presentation (James, et al., 2016). Further quantitative study into gender dysphoria and its involvement with medical

care is strongly recommended, especially into the delay of preventative and routine care for sexual and reproductive health amongst trans-masculine individuals.

The study identified that participants commonly expressed themselves as lucky or fortunate to receive respectful medical care. Given that the NCTE 2016 Transgender Survey found that 33% of trans individuals experienced at least one negative experience while seeking medical care, with 2% of individuals reporting instances of assault in a medical setting related to their identity as a transgender person (James, et al., 2016), it is not difficult to understand why there is such a pervasive belief that accessing medical care will be at the very least, uncomfortable, unpleasant, and mentally and emotionally distressing. Further investigation into how the healthcare system can ease dysphoria through medical transition is needed, which includes consideration into the legal and medical nature of transition as both separate and combined entities. When considering the long-term impact of traumatic negative experiences endured by trans individuals seeking healthcare, as well as the widespread belief that these experiences are to be expected and endured, there is a concerning unknown for an already vulnerable population.

Recommended policy and practice improvements

Intentionally inclusive practices. The data generated a picture of patients who were often surprised to see their identities reflected in signage, research study advertisements, etc. These kinds of visible signals, while less direct than rainbow or trans pride flags and safe zone signage, are an indicator of a medical provider's intentional inclusivity. The choice to ask about and consistently respect preferred name and pronouns for patients across all members of the medical team is a standard and easily implemented change that all providers can implement which shows trans patients that their identities matter.

Providers looking to become more intentionally inclusive would benefit from connecting with trans focused healthcare providers like Fenway Health, to request support and guidance on developing policies and procedures to effectively support trans patients to access PCP services. This recommendation holds especially true for pediatric medical providers, who have a unique opportunity to foster relationships with trans-knowledgeable providers to create a warm hand off and ensure that trans patients do not feel rejected or as though their needs cannot be met within their existing pediatric practice. In a macro lens, respondents to the NCTE surveys in both 2011 and 2016 cited cost as being the most significant barrier to medical care (Grant, et al., 2011; James et al., 2016), for our participants geographic limitation was significantly more impactful, however the cost of transportation and travel related expenses was also brought up. Considering how to better provide trans-knowledgeable care throughout all of Massachusetts should be a legislative and healthcare policy priority. The NCTE found that trans patients were “three times more likely to have to travel more than 50 miles for transgender-related care than for routine care (James, et al., 2016) which was observed in the data collected and analyzed to answer the research question posed. Research and policy initiatives focused on the transportation barriers for trans individuals in Western and Southeastern Massachusetts as it pertains to accessing trans-knowledgeable healthcare would likely help to determine where there are large regional gaps in care access for trans patients of all ages.

Limitations

The study interviews resulted in a wealth of data, however there were some limitations and areas of opportunity which are relevant to the results. Inherently, the use of a convenience and snowball sample recruiting method from an often isolated and disenfranchised population

results in a sample of individuals that is somewhat influenced by the geographic reach and cultural access of the research team.

The primary limitation of this study was the sample size ($n=8$). The research team recruited individuals with a goal of 10 participants, using a combination of in person and electronic recruiting contact, from convenience and snowball samples. The resulting population is not sufficient to reach saturation of grounded theory data (Aldiabat, & Le Navenec, 2018).

In addition, no participants of color were represented, which is a significant limiting factor as there is even less qualitative research data available on the experiences of people of color.

According to the NCTE studies, people of color experience higher rates of discrimination, assault, and refusal of care (James, et al., 2016) further suggesting the need for more intensive study into the experiences of transgender people of color accessing medical care.

An additional limitation on the study was the low participation from trans-feminine individuals, which is relevant to studies regarding experiences accessing healthcare, as the NCTE has found significant variety in the types and magnitude of negative experiences had while accessing healthcare as a trans individual when compared between trans men, women and non-binary individuals(Grant, et al., 2011; James, et al., 2016).

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Appendix A

Interview Guide

ATP Interview Guide

This Interview guide includes seven questions, with each subheading representing potential prompts to further and encourage discussion without asking leading/influential questions.

1. Do you currently have a primary care physician?
 - a. If Yes:
 - i. How did you find them?
 - ii. How long have you been a patient there?
 - iii. When was the last time you utilized their services?
 - b. If No:
 - i. Why?
2. Tell me about the best experience you have had with a primary care provider?
 - a. Before social/medical transition
 - i. Before change of legal documentation
 - b. After social/medical transition
 - i. After change of legal documentation
3. Tell me about the most challenging experience you have had attempting to seek medical care?
 - a. What kind of provider?
 - b. What kind of care?

- i. Urgent?
 - ii. Medical Advice?
 - iii. Preventative?
 - iv. Illness or Injury?
- 4. Tell me about the last time you needed to obtain a new medical provider?
 - a. What kind of provider?
 - i. PCP, specialist, etc
 - b. How urgent?
 - i. Same day, soon, long term (PCP)
 - c. How did you find them?
 - i. Online, referral, advertisement
 - d. How comfortable did you feel initiating care with a new provider?
 - i. What made/makes you feel comfortable?
 - ii. Did you notify your first contact that you are a transgender patient?
 - 1. If yes, what was that experience?
- 5. Tell me about your experiences with the following members of a typical medical team:
 - a. Physicians
 - i. Tell me about an experience that stands out to you?
 - ii. What makes interactions with this member of the medical team positive or negative for you?
 - b. Physician Assistants/Nurse Practitioners
 - i. Tell me about an experience that stands out to you?
 - ii. What makes interactions with this member of the medical team positive or negative for you?
 - c. Medical Assistants/Nurse
 - i. Tell me about an experience that stands out to you?
 - ii. What makes interactions with this member of the medical team positive or negative for you?
 - d. Receptionist/Scheduler
 - i. Tell me about an experience that stands out to you?
 - ii. What makes interactions with this member of the medical team positive or negative for you?
 - e. Billing
 - i. Tell me about an experience that stands out to you?
 - ii. What makes interactions with this member of the medical team positive or negative for you?
- 6. Walk me through a typical experience for you if you were to need access to medical care in the next 2-3 days?
- 7. Is there anything else you want me to know that I have not asked you about in this interview?

Appendix B

Demographic Screener

Preferred Name:	Date:	Participant Number:
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1. Please select your preferred pronouns for the purposes of the interview:

She/her He/him They/them

2. What is your sex assigned at birth: Male Female

3. What gender do you present as most of the time: Male Female Androgynous
4. What is your current age: _____
5. What race do you identify as: White/Caucasian Black/African American Asian
Native American Other: _____
6. What is your highest level of education you have achieved:
Less Than High School Diploma Associate's Degree/Certificate Program
High School Diploma/GED Bachelor's Degree
Some College Master's Degree
Trade Certificate/License Ph. D./M.D.
7. Do you currently have insurance coverage of any kind? Yes No
8. What is your current level of employment if any: (circle all that apply)
Unemployed – seeking Part Time employed
Unemployed – not currently seeking Full Time employed
Disabled Retired
Student Armed Forces (currently enlisted & veteran)
9. Do you have any medical conditions or concerns which warrant ongoing or regular medical care with a medical provider? Yes No
10. Do you identify as Transgender? Yes No I'm Not Sure
11. Which of the following terms do you feel best describe your gender identity:

Transgender Male/Masculine Genderqueer Non-Binary

Transgender Female/Feminine Genderfluid Gender Non-Conforming

Transsexual A-Gender Two Spirit

12. Which of the following document changes have you made as a part of gender related transition, if any: Legal Name Change

Gender Marker Change – Drivers License Gender Marker Change – Birth Certificate

Appendix C

Bridgewater State University Informed Consent Document

Title of Research: Experiences of Transgender Individuals Navigating Health Care Access in Massachusetts

Researchers: Nicole Tompkins-Hughes, School of Social Work, (774) 269-1076

You are being asked to participate in a project conducted through Bridgewater State University. The University requires that you give your signed consent and agreement to participate in this

project. The investigator will explain to you in detail the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask them any questions you have to help you understand the project. A basic explanation of the project is written below. Please read this explanation and discuss with the researcher any questions you may have. If you then decide to participate in the project, please sign on the last page of this form in the presence of the person who explained the project to you. You should be given a copy of this form to keep.

1. Nature and purpose of the Project: There is limited data available on the lived experience of transgender individuals, especially regarding the experience of accessing health care as a transgender or gender-non-conforming individual. Recent research studies regarding Transgender individuals' experiences of discrimination in health care settings strongly recommend the value of research focused on the experiences and stories associated with these statistics. Specifically, the need for additional research into how transgender patients find, obtain, and access medical care and advice preventatively, and as needed. This research on the experience of discrimination in healthcare settings will provide valuable information to policy makers on the needs of new legislation, and provide invested parties and service providers' information necessary to end healthcare discrimination based on gender identity.

2. Explanation of the Procedures: You will be asked to complete a one page demographic form to disclose non-identifying information regarding your age, race, gender identity, education level, level of gender related visual conformity, a history of requiring ongoing medical care for chronic illness or health conditions, and your self-identified preferred pronouns. Following this, the student investigator/researcher will ask a series of open ended questions, the answers to which will be recorded via audio only on a standalone audio recording device. Due to the sensitive nature of the interview questions, interview locations will be chosen intentionally to preserve human dignity, ensure privacy and confidentiality, and also to ensure the safety and comfort of all parties. If at any time you no longer feel comfortable participating, or do not feel comfortable responding to one or more questions, please notify the student researcher, and your interview will be ended immediately without consequence. If at any time you no longer wish to participate in the project prior to completion and publishing, you must notify the student researcher in writing, at which time any completed materials will be destroyed in such a way as to maintain confidentiality and anonymity. Following the interview, the student researcher will provide you with a list of resources available to you to support you with any emotional discomfort you experience as a result of the interview, as well as resources and supporting materials regarding your rights as it pertains to health care as a transgender person.

You should not participate in this study if you are not comfortable discussing your experiences attempting to access health care in Massachusetts as a transgender identified person. This may include, but is not limited to, those with past experiences of discrimination and assault in a health care environment who may experience emotional triggering as a result of discussing the interview questions and responses.

Your participation in the study will last through the duration of the recruiting, scheduling, and interview process. Following the interview, the student researcher may reach out to you regarding any follow up questions or needed clarifications to ensure the integrity of the transcribed and analyzed data up until the point of completion, which is anticipated to be no later than June 2020.

3. Discomfort and Risks: Risks or discomforts that you might experience include possible anxiety or emotional re-traumatization as a result of discussing past experiences of discrimination, harassment, or assault through the use of approved interview questions and potential prompt follow-ups.

4. Benefits: This study creates an opportunity to review the narrative experiences of transgender individuals as they navigate the health care system in Massachusetts, and better understand the statistics on discrimination based on gender identity. This allows interested parties to define and understand in more detail and with greater understanding the specific ways in which Massachusetts policy needs to change.

Individually, you may benefit from the receipt of educational material from the National Center for Transgender Equality regarding your healthcare related rights as a transgender identified person.

Appreciation gift: An Appreciation gift is available to you in the amount of \$10.00, funded from the Adrian Tinsley Grant for Undergraduate Research at Bridgewater State University. This gift will be provided to you at the time of your interview, and is not expected to be returned regardless of whether or not the participant chooses to terminate their involvement in the study.

5. Confidentiality: Your information will be kept confidential by the use of participant numbers assigned randomly, and the limiting of requests for sensitive and/or identifying information. Additionally, all interview and study related materials will be stored electronically in the student researcher's Bridgewater State University password protected One Drive cloud storage account. When transcribed, all instances of the subject's name and/or identifying information will be redacted or replaced with the subject's participant number where and when possible with deference to the integrity of the interview.

Additionally, while every effort will be made to keep your study-related information confidential, there may be circumstances where this information must be shared with: Representatives of Bridgewater State University, including the Institutional Review Board, a committee that oversees the research at BSU, and the faculty mentor assigned to this project. If at any time you express any desire or threat to harm yourself or others, as a mandated reporter the student researcher may be required by law to disclose this information to a supervisor or emergency services provider.

Refusal/Withdrawal: Refusal to participate in this study will have no effect on any future services you may be entitled to from the University. Anyone who agrees to participate in this study is free to withdraw from the study at any time without penalty.

By signing below I am indicating that I understand that it is not possible to identify all potential risks in an experimental procedure, and I believe that reasonable safeguards have been taken to minimize both the known and potential but unknown risks. I agree that all known risk to me have been explained to my satisfaction. I understand that Bridgewater State University has no policy or plan to pay for any injuries I might receive as a result of participating in this research protocol.

Participant Signature Date

Witness Signature Date

Any questions regarding the conduct of the project, questions pertaining to your rights as a research subject, or research related to injury, should be brought to the attention of the IRB Administrator at (508) 531-1242.

Any questions about the conduct of this research project should be brought to the attention of the principal investigator: Nicole Tompkins-Hughes, (774) 269-1076,
NTompkinsHug@Student.bridgew.edu

Appendix D

Debriefing Resources

As a result of the interview and related discussions, you may experience some emotional distress or discomfort. If this occurs, please do not hesitate to reach out to any of the following resources:

The Trevor Project - <https://www.thetrevorproject.org>

The Trevor Project offers accredited lifesaving, life-affirming programs and services to LGBTQ youth that create safe, accepting, and inclusive environments over the phone, online and through text.

Trevor Lifeline:—The only national 24/7 crisis intervention and suicide prevention lifeline for LGBTQ young people under 25, available at 1-866-488-7386.

TrevorChat:— A free, confidential, secure instant messaging service for LGBTQ youth that provides live help from trained volunteer counselors, open daily.

TrevorText:— A free, confidential, secure service in which LGBTQ young people can text a trained Trevor counselor for support and crisis intervention, available daily by texting START to 678678.

Trans LifeLine - <https://www.translifeline.org/> **US Toll Free Hotline:** 877-565-8860

Trans Lifeline is a national trans-led organization dedicated to improving the quality of trans lives by responding to the critical needs of our community with direct service, material support, advocacy, and education. Our vision is to fight the epidemic of trans suicide and improve overall life-outcomes of trans people by facilitating justice-oriented, collective community aid.

Health Care Related Rights

During the course of this interview, we discussed circumstances where you may have experienced some form of discrimination or negative interaction with a member of a medical team or provider. There are resources available to ensure that you are aware of your rights and how to protect yourself in the event of discrimination in medical environments. The student researcher has provided a packet regarding your rights and how to protect them in medical environments and when seeking medical care. This includes resources and services available to

you in the event that you experience discrimination or a negative interaction with a member of your healthcare provider's medical team. For your convenience, this information can also be found at the following URL addresses:

National Center for Transgender Equality <https://transequality.org/know-your-rights/healthcare>

Appendix E

Recruiting Materials

Seeking Trans and Non-Binary

Adults 18+ in Massachusetts

For an Interview Based Study

Researching Experiences Accessing

Healthcare in Massachusetts

Contact: Nic Tompkins-Hughes

NTompkinsHug@Student.Bridgew.edu

To schedule an in-person or remote interview

What would I need to do?

Great question! You complete a brief demographic questionnaire which is kept anonymous. Then, participate in a 7 question interview about your experiences accessing healthcare in Massachusetts. Lastly, we chat about the resources available to you as a transgender patient in Massachusetts.

That's it? Sounds easy! What's in it for me?

It is very easy, and very low key. Interviews may be conducted remotely or in person in the Greater Boston Area during through July 12th. (Availability is flexible 5am-11pm)

As a person of transgender experience, your story, voice, and opinions—de-identified—can assist with policy analysis and implementation regarding improving access to healthcare in Massachusetts. Also, a gift valued at \$10 as a thank you for your participation!

Okay, but what are the risks?

With this type of study, the risks are associated with sharing your lived experience as a transgender person, which may be emotional. Should you decide to participate, if you experience any discomfort or are feeling triggered during, the interview can be discontinued or paused.

For your convenience following the interview, a one page document will be provided which includes information and contact info for transgender-informed support and crisis organizations, as well as information about your rights as a patient.

IRB Approval #201915

Faculty Mentor Contact Info Available

